SHORT BOWEL SYNDROME PATIENT EXPERIENCE: A MIXED-METHOD STUDY LEVERAGING INSPIRE, AN ONLINE COMMUNITY PLATFORM

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Introduction

- Short bowel syndrome (SBS) is a complex condition resulting from changes in absorptive capacity of the small intestine.1
- Changes in absorptive capacity may be due to surgical resection, congenital disability, or disease of the small intestine.^{1,2}
- SBS impacts fluid, electrolyte, macronutrient, or micronutrient absorption and can cause protein-energy malnutrition.3
- Patients are often unable to meet nutritional needs through oral intake or enteral nutrition resulting in long-term reliance on parenteral nutrition (PN), fluids, and electrolytes.1
- Long-term use of central catheter can be associated with complications including sepsis, occlusion due to thrombus, and catheter related mechanical risks
- Combination of long-term PN, anatomical changes associated with SBS, and lack of oral intake or enteral nutrition can result in complications such as intestinal failure-associated liver disease.

Multidisciplinary Approach

- The role of a multidisciplinary team (MDT) is paramount considering the complexity of SBS.
- Primarily includes primary care physicians, gastroenterologists, registered dietitians, nurses, and social workers.^{4,5}
- A lack of published guidelines and treatment algorithms leads to disparities across MDTs and MDT centers.6

Financial Constraints and Employment Issues

- Increased financial constraints are common due to inadequate insurance coverage, high out-of-pocket costs, and increased healthcare utilization.
- Patients have also reported loss of wages and difficulties in maintaining employment.^{7,8}

Methods

Figure 1. Study design



Phase 1: 60-min interviews conducted via web-based

teleconferencing Phase 2: 30-min online survey



Phase 1: March 21 – April 13, 2023

Phase 2: July 25 – September 29, 2023

Study Setting and Participants

- Sample consisted of adult patients residing in the USA with a self-reported diagnosis of SBS or chronic nutrient malabsorption (CNM), and receiving home PN (HPN) for ≥ 6 months; or adult care partners of patients meeting the same criteria.
- Both patients and care partners were recruited through the Inspire online community platform with > 2.5 million members worldwide, and specifically among members in Inspire's Oley Foundation Community, supporting 38 000 members

Survey Items

- Qualitative interview content focused on the SBS patient journey, including diagnosis, management/treatment, caregiver involvement and role, quality of life (QOL) burden, and unmet needs.
- Themes emerging from phase 1 informed items for the phase 2 survey.
- The phase 2 survey included items on causes and diagnosis of SBS, treatment experience, impact of PN, mental health, and various aspects of social determinants of health (SDOH) such as housing, employment, and transportation needs.
- The care partner survey mirrored the patient survey alongside questions on their relationship with the patients and the impact of SBS on their own lives.

Data Analysis

- Thematic analysis of transcripts was conducted for the qualitative interviews.
- Survey data were summarized with descriptive statistics (mean + standard deviation, median [interquartile range], or percentage).

Qualitative Interviews

- Sample included 10 interviews; six with adult SBS patients (60%) and four with care partners who care for an adult living with SBS (40%).
- Among care partners, relationship to patients included spouses (2) and mothers of SBS patients (2).
- All respondents were residing in the USA, and the majority of participants were men (6), aged 45 years and above (5), and had some college education (8).

Quantitative Surveys

Patients with SBS

- Sixty-eight SBS patients participated in the survey; most were women (79%), younger than 45 years of age (64%), had a household income below \$50 000 (59%), and were covered by commercial/private (49%) or Medicare insurance (54%) (**Table 1**).
- Most participants had some college education (89%), identified as Caucasian (88%), and were living in suburban communities (63%) with Midwest states being the most represented (31%) (**Table 1**).

Care Partners

- Sixteen care partners of patients with SBS completed the survey.
- The majority were close family members and parents of SBS patients.
- Most care partners were women (69%), younger than 45 years of age (69%), had a household income of less than \$75 000 (56%), had some form of college degree (81%), and identified as Caucasian (81%) (**Table 1**).

Overall Burden of Disease

Patients with SBS

- Challenges with housing, employment, transportation, and care partner support were prevalent.
- Housing concerns were expressed by 29% of all patients, with less than 24% reporting owning a house or having no mortgage.
- Most respondents were medically unable to work (65%), with 3% also serving as caregivers for their family.
- Most patients (65%) were receiving follow-up care in a medical center or university, with 32% relying on family or friends for transportation needs.

Care Partners

Phase I (qual) N = 10

N = 4 SBS caregivers

N = 68 SBS patients

N = 16 SBS caregivers

Phase 2 (quant) N = 84

N = 6 SBS patients

- Two care partners (12%) were concerned about losing housing in future, the majority (94%) were living in the same household as their loved ones, and 50% had spent more than five years providing care.
- The majority of care partners' loved ones were receiving care in hospital or medical center (63%) and were also responsible for providing transportation (75%).

Causes and Diagnosis of SBS

Patients with SBS

- For most patients, factors that led to SBS diagnosis were functional gastrointestinal (GI) disorders (54%), and surgery to repair damage to small intestine because of underlying disease (37%).
- Only 44% of all respondents reported receiving a formal diagnosis of SBS, 10% were still unsure if their CNM was related to SBS, and 63% were diagnosed less than 10 years ago.
- Most patients (78%) were diagnosed by a gastroenterologist specialist, 50% had a nutritionist, and 47% had a SBS specialist involved in their care. HPN was administered daily in 79% of patients.
- Of the 32 patients (47%) who reported having an SBS specialist involved in their care, 19 (59%) were referred after diagnosis. Of these patients, 11 (59%) were referred more than 6 months after diagnosis.

Care Partners

- Most care partners reported functional GI disorders as a top factor leading to SBS symptoms and diagnosis.
- Other conditions experienced by their loved ones were central line infections (63%) and trouble maintaining weight (56%).

Table 1: Characteristics of patients and care partners Care partners (N = 68) $(N = 16^{\alpha})$ Age, mean (SD), years 42.0 (14.9) Age, n (%), years 8 (12) 12 (18) 23 (34) 35-44 11 (16) 45-54 55-64 Gender, n (%) 12 (18) 54 (79) Female 2 (3) Non-binary Ethnicity, n (%) 2 (3) Hispanic/Latino/Spanish origin 66 (97) 13 (81) Not of Hispanic/Latino/Spanish origin Race, n (%) 0 (0) American Indian or Alaskan Native Asian Black or African American Native Hawaiian or Pacific Islander 60 (88) 13 (81) White or Caucasian 2 (3) Other Highest level of education, n (%) 0 (0) Some high school, but did not graduate 3 (4) High school graduate or GED 27 (40) Some college, but less than a bachelor's undergraduate degree 21 (31) 6 (38) College bachelor's degree/undergraduate degree 12 (18) Postgraduate degree (Master's, Doctorate, etc.) 5 (7) Trade school, professional program 0 (0) Prefer not to answer Region, n (%) 17 (25) 3 (19) Northeast 16 (24) 6 (38) South 21 (31) Midwest 14 (21) West BMI, n (%) 15 (22) 0 (0)b 25-29.9 30-39.9 0 (0)_p 40+

BMI, body mass index; GED, general educational development; SD, standard deviation. ^aOne care partner did not provide demographic information beyond gender and location. ^bNot applicable.

Impact of Treatment on Quality of Life (QOL)

Patients with SBS

- Patients reported severe impact on their ability to work and travel, and a slightly negative impact on ability to maintain social commitments (Figure 2).
- Mean summary score for the SBS-QOL Questionnaire was 118.5 on a scale of 0–170, with most patients (81%) reporting scores greater than 100, indicating relatively poor QOL (**Table 2**).
- Patients with a normal or overweight body mass index and a household income of more than \$100k had a relatively better QOL than those who were underweight or obese with a household income of less than \$50k (Table 2).
- Average travel time to a healthcare provider (HCP) was more than 1 hour for 25 patients (37%).

Care Partners

- Most (95%) reported supporting loved ones with household chores, and with their HCP appointments.
- Care partners were impacted the most in their ability to be intimate with their loved ones.
- Half of the care partners (50%) reported an impact on their ability to work and the majority (63%) reported an impact on their outlook for the future.

Table 2: Quality of life (QOL) Score by patient characteristics (N = 68)SBS-QOL (continuous), mean (SD) 118.5 (31.6) SBS-QOL (categorical), n (%) 12 (17) 101-170 **Patient characteristics** Gender, mean (SD) 119.6 (37.4) 118.2 (30.9) SBS diagnosis history, mean (SD) 111.8 (39.2) SBS diagnosis 123.7 (23.2) No SBS diagnosis BMI, mean (SD) 136.1 (20.7) < 18.5 111.0 (32.4) 18.5-29.9 144.4 (10.0) Income levels, mean (SD) 127.4 (24.3) < \$25K 126.7 (21.7) \$25k-\$50k 121.7 (21.7) \$50k-\$75k 104.3 (54.5) \$75k-\$100k 99.7 (26.6) \$100k+ CG support history, mean (SD) 115.7 (36.1) Has history 122.6 (23.1) No history Depression history, mean (SD) 123.9 (25.3) Has history 110.0 (41.8) No history Teduglutide use, mean (SD) 132.7 (23.0) 115.7 (32.4) BMI, body mass index; CG, caregiver; QOL, quality of life; SBS, short bowel syndrome; SBS-QoL, Short Bowel

Social Determinants of Health (SDOH) and Financial

Patients with SBS

Syndrome Quality of Life Questionnaire; SD, standard deviation.

- Most respondents (65%) had at least one SDOH issue, with the leading issue being the ability to pay bills for copays, medication, and procedures (reported by 47%; **Figure 3**)
- Other SDOH concerns reported included fear of losing their home (29%) and low household income (< \$50k; 59%).
- Among those who had issues with paying medical bills (32 patients), 69% had a delayed prescription or none to fill, and 59% had delayed or canceled visit to a HCP.

Care Partners

 Most care partners (62%) supported their loved ones in managing their medical bills.

Mental Health

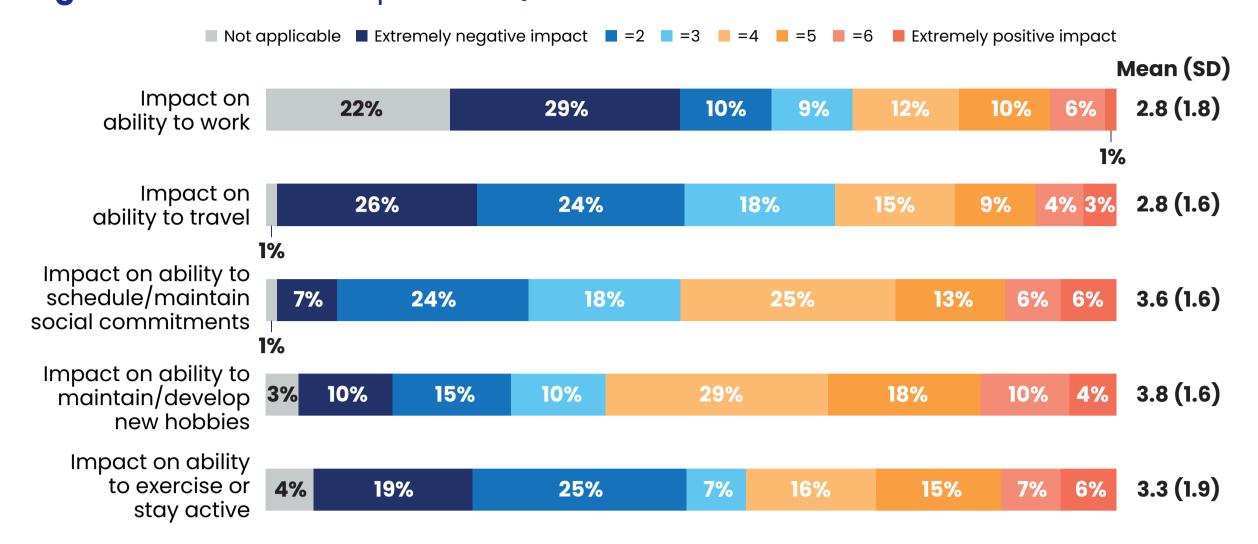
Patients with SBS

- Depression rates were high (65%) with most reporting diagnosis or suspicion of depression.
- Despite a high prevalence of depression, only 46% were meeting with mental health professionals.

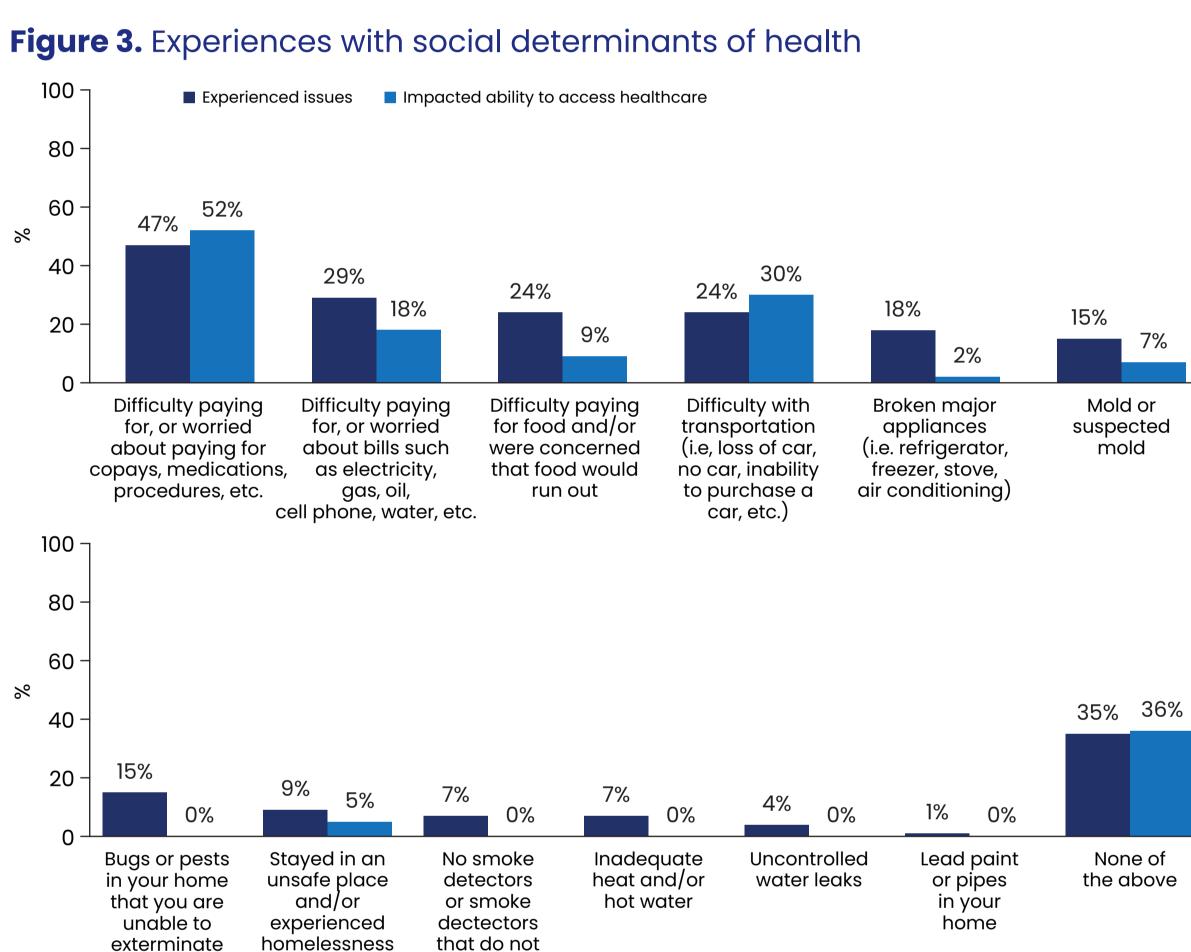
Care Partners

 More than one-third (37%) were diagnosed or suspected of having depression, with most (67%) not under the care of a mental health professional, indicating low utilization of mental health services.

Figure 2. Treatment impact on QOL



P450. On a scale of 1–7 where 1= extremely negative impact and 7 = extremely positive impact, to what extent does being Base: Patients currently receiving PN (n=68) on home parenteral nutrition impact the following?



Conclusions and Limitations

- This mixed-method study leveraged an online community platform, demonstrating the physical limitations of SBS and its impact on QOL, SDOH, and mental health for both patients and care partners.
- Longitudinal research is warranted, and Inspire is uniquely positioned to understand and measure the impact of treatment options over time in this underserved SBS population.

Limitations

- Study results may not be generalizable to all SBS patients or care partners.
- Absence of International Classification of Diseases, 10th revision codes for SBS led to a lack of awareness of formal diagnoses, and therefore presents a challenge in identifying SBS patients.
- Recall bias among patients and care partners may exist.

Strengths

• The use of a mixed-method quantitative survey with further qualitative exploration through 1:1 discussions and thematic analysis provides a more comprehensive understanding of the complex dynamics of the condition. Cross-validation of findings enhanced the reliability and validity of the results.

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employed by Takeda and receive stock and/or stock options. **Cheney Matthews** and **Bram P Raphael** are former akeda employees. **Manpreet Mundi** is an employee of Mayo Clinic and has received remuneration for research consulting from Inspire. *Jordan Richardson is a former Inspire employee and has elected not to remain involved in the poster development.